

## Towards a national bioethics committee

*Wanted: a new strategic body to deal with broad issues*

Over 500 MPs turned out for the votes last week on embryo research and abortion—clear evidence of the public's concern with bioethical issues. Public feelings also run high on topics such as organ transplants and gene therapy. Yet on two issues (abortion and embryo research) governments have given MPs a free vote, without providing a clear and authoritative source of professional advice or a collective lead on the wider ethical and policy issues. Several other countries have a single body to which bioethical problems can be referred for assessment—and which can anticipate new ones. Britain has referred difficult and contentious issues piecemeal and as they arise to individual bodies not primarily concerned with ethical matters such as the Department of Health, the Medical Research Council, the medical royal colleges, and the BMA. It has set up ad hoc expert committees to consider individual problems that could be ignored no longer—for example, the interim licensing authority on in vitro fertilisation. And it has also consulted special interest groups including the pharmaceutical industry, religious bodies, and consumer organisations. But we have lacked a national body to keep the issues under review and it was left to the MRC and the Royal College of Obstetricians and Gynaecologists to set up the interim licensing authority on in vitro fertilisation.

It must seem to outsiders quite extraordinary that the House of Commons now has no forum for discussing these matters—and not even a committee specifically concerned with science (though the Lords retains its select committee on science and technology). The need for a standing committee at national level specifically devoted to medical ethics is not only a matter of allaying public alarm. Last year the European Parliament adopted two reports which if approved by the Council of Ministers might prohibit the member countries from carrying out important research in medicine and agriculture—such as on pre-embryos, the human genome, and genetically manipulated organisms. With this threat, however remote, and the call for all member states to establish national councils of medical ethics interest in establishing a British committee has acquired a new urgency. The Ciba Foundation and Gresham College debated this proposal at a seminar last autumn, and it was discussed at greater length at a Nuffield Foundation Conference on 20-22 April.

Experience in at least three countries is relevant to these recent discussions. Two years ago the Australian government established the National Bioethics Consultative Council with the aim of achieving a national uniform approach. It provides advice and undertakes studies on major new developments—

for example, on surrogacy and access to reproductive technology. Establishing the National Ethics Council in Denmark almost precipitated the fall of the government, yet it is now said to be well established and is currently dealing with embryo research, preimplantation diagnosis, and gene therapy. The most conspicuously successful of these bodies, however, the President's Commission in the United States, was discontinued by President Reagan—a disappointing outcome to a successful venture given that between 1980 and 1983 it published no fewer than 10 high quality reports, including those on stopping life sustaining treatment and protecting human subjects of research.

There is, then, a good case for considering a new national body in Britain to study similar problems. We need to tease out not only the details of its remit but also of its make up and resources. Such a committee should not be a national research ethics committee, something which is also urgently needed. A research ethics committee should deal with monitoring, training, and coordination (and is the responsibility of bodies concerned with audit and standards), whereas an advisory committee on biomedical ethics should have a strategic and advisory role, dealing with broad general bioethical issues as they arise and assessing their impact on our lives and in particular on those who may be directly affected by the evolution of research.

From experience in other countries at least three features should be borne in mind. Firstly, these committees are easier to create before controversy becomes acute, as was the problem in Denmark. Secondly, they should be insulated from political pressures. In Belgium, for example, the recent problems in passing the abortion act have made the formation of a national body impossible. Thirdly, the membership should be small and chosen on the basis of individual skills and experience. France has had a national bioethics committee since 1983, yet, with 37 members (each serving for four years and some representing various interests), progress has been limited. Moreover, French practice has been based on developing new attitudes by devising statutes rather than codes of practice. Here again a lesson could be learnt from another country. In Australia the chairman of the national consultative committee, Judge Layton, has stated that legislation is too cumbersome for a fast changing topic such as reproductive technology. "In circumstances where we have different convictions on a moral issue, to attempt to settle the question by prohibitive legislation is not in my view the best way of control."

The United States President's Commission provided a successful model of an influential committee. This had 11 members, distinguished in various specialties—three from medical or behavioural research; three from medical practice; and five from other disciplines such as ethics, theology, law, social sciences, and public affairs. The 18-20 staff members included research assistants, consultants, and a public information officer, and some were seconded from the universities. As well as commissioning various studies from outside experts the commission prepared documents in house, took evidence from expert witnesses, and held a two day public meeting every month.

The working of any new committee cannot be fixed in advance but must depend on how it finds its tasks in practice, together with the results of wide consultation. Thus progress should be deliberate, with the initial ideas circulated in a discussion document before any conclusion is reached.

Nevertheless, if the committee is to carry weight with the research community some must be included among its members who have the distinction to carry authority with scientists, the public, and the government. It must not be seen or indeed act as a mere talking shop and it should seek to establish some link with parliament. Nor must it be dominated by senior eminent figures retired from their mainstream careers. Indeed, there is a strong case for all scientific advisory committees to have an upper age limit for their members. It must be adequately funded and, while it must remain independent, the government should be willing to contribute to its running costs. There is a good case for following the evolution of the committee on in vitro fertilisation, with its progression from a voluntary through an interim to a planned statutory basis.

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## Meningococcal meningitis

### *A diagnosis not to be missed*

Bacterial meningitis is a medical emergency; delay between suspicion of the diagnosis and treatment increases both morbidity and mortality. Symptomatic infection with meningococci is uncommon: there were 1142 notified cases of meningococcal meningitis and 228 of meningococcal septicaemia in England and Wales in 1989, with a total of 203 deaths.<sup>1</sup> The Royal College of General Practitioners' weekly returns service statistics show that the average general practitioner sees fewer than one patient each year with meningitis. Thus doctors of first contact have to have knowledge out of proportion with their previous experience.

The diagnosis of meningococcal meningitis is easy in a febrile child with a history of headache, signs of meningeal irritation, an altered level of consciousness, and a petechial rash. Such knowledge of a classic presentation may be falsely reassuring. Meningococcal meningitis is not exclusively a disease of childhood: in Britain in 1989 group B meningococcal strains showed an increased incidence in teenagers. In the very old or the very young headache may not be obvious if the conscious level is impaired. Neck stiffness may not be apparent. Fever may be absent in the very old, the very young, or the very ill. The initial rash may be a non-specific maculopapular eruption. During epidemics of meningococcal meningitis a rash may be found in half or more of patients, and at other times a rash is found in probably no more than 10-20%.<sup>2</sup> This leaves many patients in whom a rash is not present. The rash may be only in regions of pressure on the skin, and if patients are not fully undressed such lesions may be missed. In some patients the only lesions may be small petechiae in the palpebral conjunctivae. Finally, patients with fulminant meningococcal septicaemia may die before meningitis has time to develop.

The diagnostic problems posed by the factors above justify sensible but dogmatic clinical guidelines. Urgent hospital admission is mandatory in the circumstances shown in the box.

All patients who present in the community should be given intravenous benzylpenicillin before transfer to hospital if meningococcal infection seems likely. This may be life saving but may render blood cultures sterile—but the causative organism may still be grown from the cerebrospinal fluid, and

Hospital admission is mandatory in:

- All febrile patients who have signs of meningeal irritation
- All patients who develop a petechial rash who are unwell, febrile, or hypotensive
- Febrile patients whose conscious level is impaired
- Any patient who has a fit in relation to a fever (a possible exception being a child with a history of febrile convulsions)
- Feverish or unwell babies who have a bulging fontanelle—a bulging fontanelle in babies with vomiting (who should be dehydrated) is highly suggestive of meningitis
- Patients with any illness, especially headache or feverishness, who are close contacts of patients with meningococcal infection, even if they have received a prophylactic antibiotic.

bacterial antigen detection will usually give positive results when performed on the cerebrospinal fluid.<sup>3</sup>

If the diagnosis of meningococcal infection is likely then the referring doctor should notify the appropriate community medicine specialist (consultant in public health medicine or communicable disease control), initially by telephone. If the diagnosis is less certain we recommend that the referring doctor telephones the hospital two hours later to discover its opinion. If the diagnosis is confirmed the referring doctor should tactfully ensure that the community medicine specialist has been notified.

The community medicine specialist has the duty to control infection in the community: he or she should advise general practitioners on preventing secondary cases by administering prophylactic antibiotics to all close contacts, no matter what their age, as soon as is possible. Prophylaxis should not await the results of investigations because studies have shown that invasive meningococcal infection may develop soon after acquisition of the organism.<sup>4</sup>

The definition of close contacts is important but difficult,